

**Schizophrenia Society of Ontario's Submission to the Ontario Legislature's Standing Committee on
Finance and Economic Affairs
2017 Pre-Budget Consultations
January 20, 2017**

The Schizophrenia Society of Ontario (SSO) appreciates the opportunity to respond to the Ontario Legislature's Standing Committee on Finance and Economic Affairs 2017 pre-budget consultations.

About SSO

SSO is a charitable health organization that supports individuals, families, caregivers and communities affected by schizophrenia and psychosis across the province. For over 30 years we have made positive changes in the lives of people affected by schizophrenia by building supportive communities through services and education, advocating for system change and conducting research into the psychosocial factors that directly affect mental illness.

SSO has long advocated for improved access to mental health care, including psychiatric care (i.e., medication, hospital-based care, psychiatrists); community-based mental health services (e.g., case management, counselling, peer support); and social supports (e.g., housing, income, employment, social participation).

This submission is informed by our extensive history working with people affected by chronic and complex mental illness* and their families in Ontario and our recent cross-Canada engagement with people with lived experience and the organizations that represent them.

Continued Collaboration

A long-standing member of the Ontario Disability Support Program (ODSP) Action Coalition and the Ministry of Community and Social Service's (MCSS) Disability Adjudication Working Group, SSO is committed to collaborating with community partners and government to improve social assistance and address poverty in Ontario, including through our most recent efforts to simplify the medical review process so that it is more efficient for social assistance recipients and their health care providers. Most recently, we have endorsed Health Quality Ontario's (HQO) Schizophrenia Quality Standards for Care for Adults in Hospitals and we will be participating in the development of the agency's Schizophrenia Quality Standards for Care in the Community. Through our Justice and Mental Health Program, SSO has identified the criminalization of mental illness as a key advocacy area; specifically, we have prioritized segregation as an issue that significantly affects people with schizophrenia and other serious mental illness and have been vocal advocates for reform in this area. Lastly, we have recently partnered with

* In this submission, the terms "serious mental illness" and "chronic and complex mental illness" are used interchangeably to refer to symptoms and conditions which may take the form of changes in thinking, mood or behaviour, or some combination of all three, that significantly impact a person's ability to function effectively over a prolonged period of time. These terms are used because they are relevant to our recommendations. It should be noted that not all individuals living with a persistent mental health issue would identify with these labels.

health organizations outside of the mental health and addictions sector to address common barriers to accessing medications across Canada.

About schizophrenia and psychosis

Schizophrenia is a serious but treatable mental illness affecting about one per cent of Canadians. Although experiences vary, it is generally characterized by symptoms of psychosis, such as hallucinations, negative symptoms, such as social withdrawal, and thought disorder, which can include disorganized speech. Psychotic illnesses, such as schizophrenia, can affect anyone, irrespective of culture, race, socioeconomic status, or gender and onset usually occurs between the ages of 16 and 24.

A recent Ontario study found that there are 142,821 people living with a chronic psychotic illness in the province (just over one per cent of the total population). Of these individuals, about 17 per cent had a psychiatric hospitalization in the year of analysis, averaging two hospitalizations and a length of stay of 49 days. This is in line with a recent report by HQO and the Institute for Clinical Evaluative Sciences which found that in Ontario, hospital readmission rates within 30 days for a diagnosis of schizophrenia or psychosis was 12.5 per cent – the highest readmission rate among mental illness or addictions. According to the report, this could reflect a worsening of condition or equally alarming, a lack of access to quality care in the community.

The same report found that in Ontario, less than one-third of patients hospitalized for mental illness or addiction have a follow-up visit with a doctor within seven days of leaving hospital. In contrast, 44 per cent of patients hospitalized for heart failure will see a doctor within seven days of discharge. By type of mental illness or addiction, the lowest rate of follow-up visit within seven days is among people who have been hospitalized for schizophrenia or psychosis. The report again suggests that this could signify problems with transitions in care from the hospital to the community.

Despite the presence of symptoms or diagnoses, recovery is possible and is a nonlinear, individual process. Sustainable access to a combination of medical supports, community-based services, social and informal supports is essential for achieving both good health and quality of life, yet Ontarians living with serious mental illness are still not getting the help they need.

The need for investment

The Ontario government is clearly committed to improving access to mental health care and supports for children, youth and adults. Through its numerous initiatives to improve access to care, including Ontario's Comprehensive Mental Health and Addictions Strategy, *Open Minds, Healthy Minds*, the Patients First Action Plan for Health Care, the *Excellent Care for All Act* (2010), the Poverty Reduction Strategy and Expert Advisory Panel on Homelessness, and the Long-Term Affordable Housing Strategy Update, the province is on the right track to addressing significant gaps in a historically neglected sector.

Recent investment allocations to Local Health Integration Networks for mental health and addictions services, Ontario First Nations mental health, provincial prison mental health, and housing with mental

health supports are fundamental to implementing these strategies and ensuring better outcomes for people with mental illness and addiction.

The province's Mental Health and Addictions Leadership Advisory Council has identified five priority areas for system transformation: prevention, promotion and early intervention; youth addictions; supportive housing; system alignment and capacity; and funding reform. SSO strongly supports the Council's work in these areas and the recommendations in this submission are well aligned with these priorities.

Nonetheless, despite the progress that has been made, the need for further targeted investment persists. People with chronic and complex mental illness continue to experience disproportionate rates of poverty, homelessness and/or precarious housing, contact with the criminal justice system and difficulties accessing community care and social supports, placing people at higher risk for poor health outcomes.

Through our work we have seen the devastating impact that persistent barriers to accessing timely mental health care can have: (re)hospitalizations, contacts with police, social isolation, poverty and, most tragically, deaths by suicide. In fact, the lifetime risk of suicide among persons with schizophrenia is between four and 10 per cent. In addition, although research on the prevalence of mental health issues in Canada's prisons varies, it is estimated that mental health issues are two to three times more common in prison than in the general community. Moreover, studies in various Canadian cities indicate that between 23 and 67 per cent of people who are homeless report having a mental illness.

These statistics are staggering for many reasons, among them the fact that the average cost per day of hospitalization in a speciality psychiatric hospital in Ontario is about \$787 to \$1,138 and detention in an Ontario adult correctional institution is approximately \$198 per day. It is estimated that direct and indirect costs of mental illness to the Canadian economy are over \$50 billion and rising, with schizophrenia accounting for the highest expense in terms of direct costs to the health system such as medications and hospitalizations. At the same time, cost-effective, evidence-informed programs and services exist, such as specialized Early Intervention (EI) services, Assertive Community Treatment (ACT) teams, Cognitive Behavioural Therapy (CBT) and supportive housing, which prevent relapse and re-hospitalization and divert people out of the criminal justice system, however they remain difficult to access for many Ontarians due in large part to a lack of services, particularly in more remote areas.

What is more, the costs of serious mental illness to families/caregivers can be profound and far-reaching. Barriers to comprehensive and early treatment and inadequate supports for caregivers contribute to emotional and financial costs to families/caregivers. Often families/caregivers have to fill in gaps due to a lack of sufficient community-based supports. Many incur significant out-of-pocket expenses for essential mental health care for their relative, such as medications and psychotherapy, and their productivity at work may be impacted by their caregiver responsibilities. In fact, the Ontario Caregiver Coalition highlights that there are 3.3 million unpaid caregivers, with 76 per cent juggling their caregiving responsibilities with paid employment; remarkably, 35,000 have reported being terminated or having to quit their paid employment due to caregiving duties.

Recommendations

To achieve better system coordination, better access to mental health treatment and supports and ultimately improve mental health outcomes for Ontarians, significant investment in mental health services and supports continues to be critical. Mental health care in Ontario remains grossly underfunded – according to statistics posted by the Centre for Addiction and Mental Health, mental illness accounts for about ten per cent of the disease burden in the province, yet only receives seven percent of health care dollars; relative to this burden, mental health care in Ontario is said to be underfunded by about \$1.5 billion.

The 2017 budget is a prime opportunity to create sustainable and transformative change before the 2018 provincial election.

To ameliorate the historical neglect of the mental health sector, Canada’s Mental Health Strategy recommends increasing the proportion of health spending nation-wide that is devoted to mental health by two per cent and similarly increasing social spending dedicated to mental health by two per cent from current levels by 2022.*

In line with this, SSO urges the province to commit to this recommended Canadian average by increasing its mental health spending to nine per cent of total health spending and to increase its share of social spending on mental health by two per cent.

Specifically, SSO recommends that this investment be targeted to the following areas.

1. Access to community mental health services and supports

Unlike with other health conditions, according to a Mental Health Commission of Canada report, only one in three Canadians who experience a mental illness – and as few as one in four children and youth – report that they have sought and received services and treatment. There are many reasons for this, including stigma and other barriers to accessing effective care. Currently access to mental health and addictions care depends on factors such as what publically funded services are available where one lives; wait times; and socioeconomic status.

In the case of schizophrenia, although an estimated one per cent of people – equating to 136,000 Ontarians in terms of the current population – have schizophrenia, 2015/16 figures from the Ministry of Health and Long-Term Care’s health data branch show that a mere 11,544 individuals were actually served by ACT teams and only 10,959 by EI services. According to ConnexOntario data, the average wait times for schizophrenia-and psychosis-specific services across LHINs is 42 days. The Access Point, which provides coordinated access to mental health and addictions services in Toronto, advises that in Toronto alone the wait for case management services can range from eight to 12 months and more than one year for ACT services.

* The 10 year strategy was launched in 2012.

When someone in need of care waits to receive help they could risk symptom relapse, emergency room visits, contact with the criminal justice system, loss of motivation to seek care, and possible loss of life through suicide.

At the same time, research shows that specialized Early Psychosis Intervention (EPI) services yield better outcomes than standard care after the onset of psychosis, and that those outcomes related to both clinical and treatment costs are maintained years after the intervention was provided. One study from the United Kingdom on EPI found that its participants were significantly more likely to be in paid employment than their peers who did not participate in the program and that the health care costs to treat each person were approximately \$6,300 less per year than the costs to treat those who did not receive the service. Studies also show that ACT services have been found to significantly reduce hospitalizations and homelessness among individuals with schizophrenia; what is more, psychosocial programs, such as supported employment and skills training programs, are recognized as part of standard best practice for treatment of schizophrenia.

Furthermore evidence finds that CBT interventions for people with schizophrenia both improves symptoms and results in a significant reduction in relapse, time to relapse and number of days hospitalized. CBT is also an effective treatment for symptoms of anxiety, depression and substance use, which some people with schizophrenia experience co-morbidly. There are, however, gaps in the number of professionals who are trained to deliver CBT in Canada and many people are precluded from accessing these services because of limited publically funded resources and inability to afford paying privately for therapy. SSO's CBT for psychosis pilot, which is primarily focused on providing families with CBT-informed techniques, exceeded registration capacity when costs for participation were subsidized demonstrating the high demand for affordable evidenced-based tools for people and caregivers.

The Mental Health and Addictions Leadership Advisory Council identified system alignment and capacity as a priority, including identifying a basket of core mental health and addictions services that should be available to all Ontarians and that cover the full range of individual/family/caregiver needs. To ensure system capacity and quality, investment to follow through on their findings and recommendations is essential.

For these reasons, SSO recommends investing in a basket of core mental health and addictions services, particularly for those with chronic and complex mental illness, including EPI, ACT services and psychotherapies such as CBT.

2. Income security

Onset of schizophrenia is generally in adolescence or early adulthood, often resulting in a disruption in academic and career pursuits. At the same time, stigma towards mental illness, discrimination and lack of accommodation may result in the marginalization of people with schizophrenia from the workforce. In fact, according to 2014 data from MCSS, more than a third of ODSP recipients had mental illness as a primary condition with psychoses, such as schizophrenia, accounting for 20 per cent of these cases.

At the same time, social assistance rates for people on Ontario Works (OW) and ODSP remain untenably low, resulting in social assistance recipients living far below Canada's standard measures of poverty. The Income Security Advocacy Centre points out that the average total income of a single person on OW is \$785 per month and that of a person on ODSP about \$1,200 per month – 43 per cent and 66 per cent of the Low-income measure after tax respectively – creating a struggle for people to meet even basic needs such as rent and food.

MCSS has committed to reforming income security in Ontario through the establishment of an Income Security Reform Working Group and through the development of a Basic Income Pilot. These are positive strides for broader structural change, but direct investment in social assistance rates cannot wait – the costs to society are far too great with a recent report indicating that the cost of poverty in Toronto alone is \$4.4-\$5.5 billion per year. SSO has long called for rates to be increased by 10 per cent as a modest improvement to income.

As such, we support the Interfaith Social Assistance Reform Coalition's call for \$1 billion to be allocated accordingly:

- \$700 million for a 10% increase to rates, including more for single people on OW who currently have the lowest incomes, and family members of people with disabilities on ODSP who have not had an increase for four years.
- \$300 million for rule changes to improve the OW and ODSP programs now, while longer-term systemic reforms are being considered. The ODSP Action Coalition supports a number of recommended rule changes that could be implemented to significantly improve the system, including increasing ODSP's flat-rate earned income exemption from \$200 to \$500 to enable people to keep more of the money they earn.

3. Supportive housing for people with mental illness

The lack of available supportive housing in Ontario is another significant barrier for many individuals living with mental illness. The 2016 Annual Report of the Office of the Auditor General of Ontario found that there were over 12,300 supportive housing units in Ontario as of March 31, 2016; however, it is estimated that Ontario would require approximately 38,000 supportive housing units to meet the province's current need. As part of its Mental Health and Addictions Strategy, Poverty Reduction Strategy and Long-Term Affordable Housing Strategy Update, Ontario is creating 1,000 more supportive housing units designated for people with mental illness and addictions and has committed to utilizing a Housing First approach to help combat homelessness. Although this is a positive investment, it is a modest step to meeting the growing demand.

As a result of the overwhelming demand and lack of supply, wait times for supportive housing are increasingly lengthy. Although Ontario does not have centralized data to help measure exact wait times, in regions that do track this information, it can take as long as seven years for people to access supportive housing. Individuals may not receive proper supports while waiting for housing, which can lead to a higher risk of homelessness, criminalization, and mental health crisis. Furthermore, the current system lacks coordination and works on a primarily "first-come, first-served" basis, which means that

individuals on wait lists receive available housing based on the order they applied rather than on need so those who are transitioning out of other systems (such as hospital) are left in an especially vulnerable position.

The Auditor General's 2016 annual report found that within the last five years, about one in 10 beds in specialty psychiatric hospitals was occupied by patients who no longer needed to be treated in hospital but who could not be discharged due to the lack of supportive housing or long-term care homes. This is significant because it is both more costly to keep someone in hospital who is no longer in need of hospital care and less efficient as hospital beds that could otherwise be available for people in need are unnecessarily occupied. In fact, the report surmises that in 2015/16, if the four specialty psychiatric hospitals had been able to discharge their patients as soon as required, the cost of caring for these people in supportive housing or long-term-care homes would have been \$45 million less, and the hospitals would have been able to treat about 1,400 more people.

Given that their needs may change over time, individuals with serious mental illness may have difficulty maintaining housing without the right supports in place to help them. For this reason, a coordinated, responsive and adequate supportive housing system, which contains a spectrum of supports, including Housing First, would play a significant role in reducing homelessness among this population. This in turn would help yield significant cost savings to health and social systems.

For these reasons, SSO recommends increasing investment in supportive housing for people with mental illness and addictions to better meet the current demand and to improve system coordination.

4. **Diversion**

It is well known that people with mental illness are over-represented in the criminal justice system. Studies suggest that for three out of 10 people with mental illness, the pathway to mental health care is through police. There are many reasons for this including negative stereotypes and misconceptions about their risk of violence; crimes which are directly related to the symptoms of their conditions, such as causing a disturbance, mischief, or minor theft; and the role of police as first responders to mental health crises.

At the same time people with mental illness experience significant challenges when detained, including barriers to accessing mental health treatments and supports, disproportionate placement in solitary confinement and increased vulnerability in an environment that is punitive, distressing, crowded, violent, and often unpredictable. The outcomes of this can be profound, including potential exacerbation of existing mental health symptoms, increased challenges with reintegration, increased risk of recidivism and, in the most severe cases, increased risk of self-harm and suicide.

We are encouraged by the Ministry of Community Safety and Correctional Services' current segregation review and steps for reform, including mental health training for correctional officers, as well as recent investments in mental health care in Ontario prisons. We also commend the Ministry of the Attorney General's commitment to expand and enhance the Bail Verification and Supervision programs in Ontario.

To strengthen the work that is being done on reforming corrections in Ontario, we support further investment in programs that divert people with mental illness out of the criminal justice system entirely, and into appropriate mental health and addictions treatment and support, including pre- and post-charge diversion programs and mental health courts. According to research cited by the John Howard Society, community sanctions and community corrections for adults and youth are found to be more effective and affordable responses to crime; involvement in diversion also avoids the negative effects of incarceration on individuals.

As such we recommend the expansion of diversion programs to divert people with mental illness out of the criminal justice system, including improved screening of people who may be eligible for such programs.

5. Access to medications

Medications are used to treat a wide range of mental health conditions and illnesses. Medication treatment is not a “one size fits all” model and often finding the right medication, or combination of medications, is a trial and error process which can change and evolve over the course of one’s illness. At the same time, accessing medications can be challenging. One’s ability to benefit from a particular medication treatment is often contingent on their ability to pay for it. For many individuals and families, paying out-of-pocket for their medication is often impossible – even if it is the most appropriate medication for them – and many forgo treatment altogether due to cost-related barriers. In fact one in 10 Canadians do not take their medications as prescribed due to prohibitive costs.

Research shows that even small direct costs to filling a prescription, such as dispensing fees, co-payments and/or deductibles, may dissuade a person from taking recommended medications. Although people with high medication costs can benefit from the Trillium Drug Program, for instance, the quarterly deductible can be financially prohibitive for lower-income Ontarians.

What is more, Ontario’s current patchwork medication coverage system can be onerous for people and families/caregivers to navigate. For instance, if a person transitions from the hospital to the community or from a private insurance plan to a public program, their access to medications changes, including which medications are available for coverage, how much they will be paying for accessing these medications and the administrative processes required by the program. What is more, access to some evidence-informed medications can be severely restricted. In the case of clozapine used to treat schizophrenia, the medication is currently available in Ontario for people with “treatment-resistant” schizophrenia through the Special Drug Program. Such restrictions, and the extensive administrative requirements to administer the medication, may impede prescribing practices and by extension, a person’s ability to access the medication even if it is the most appropriate treatment for them.

As a result, people often have to try medications that they can afford, rather than medications that they and their doctor determine are best for them. This impacts treatment efficacy and treatment adherence and ultimately undermines an individual’s recovery.

As such, SSO commends the province for initiating a review of Ontario's Public Drug Programs and recommends investment in expanding access to prescription medications for all low-income Ontarians regardless of their health care costs.

Caregiver support

Families/caregivers often provide crisis intervention, encourage and support treatment, arrange for income assistance, provide housing, assist with the activities of daily living, assist health care professionals and advocate on behalf of their relatives/friends. Research also finds that working with families seems to be one of the most effective ways of delivering community-based intervention to people with schizophrenia. Studies of different types of family-based interventions, including psychoeducational programs, reveal that as an adjunct to routine treatment and care for the person with schizophrenia, these interventions can enhance family members' knowledge about the illness, reduce family burden and delay patients' relapse.

Although the caregiving relationship has notable benefits for both the caregiver and the individual and has been shown to provide major savings for the mental health and addictions system by decreasing rates of hospitalization and involvement with the criminal justice system, there are numerous challenges to this role.

A national survey of Canadian family caregivers (including people caring for adults living with mental illness) found that about 60 per cent of family caregivers pay out-of-pocket expenses (primarily transportation- and medication-related costs), with 30 per cent spending over \$300 each month. In large part, these expenditures compensate for inadequate social assistance incomes for the person living with mental illness, along with insufficient and frequently inadequate housing and other necessities for social participation – as a result, some family caregivers may risk sharing the poverty of the person living with mental illness.

What is more, families and other “informal” caregivers are often neglected in the mental health system and social services with their contributions often taken for granted and their experiences as caregivers largely ignored by mental health professionals. This has a significant impact on their day-to-day living, health, social and family relationships, careers and financial situations.

To help ensure that caregivers can continue to provide this essential support, funding should be targeted to increasing supports for people in this role, including community programs and family interventions.

As an agency member of the Ontario Caregiver Coalition (OCC), SSO also supports the OCC's call for funds to improve respite care by expanding respite services and identifying and promoting innovative respite models. Such investments would help to alleviate the emotional, psychological and physical demands that caregiving commonly places on people. Specifically, the OCC supports calls for an investment of \$20 million over two years to improve respite services and their delivery for Ontario

caregivers. The total funds will be targeted towards four sub-categories of services or supports: caregiver accounts, in-home respite, day programs and overnight respite. The investment will provide approximately 4,000 caregivers with improved access to and availability of high-quality respite services.

6. Data collection and management

In their first annual report, the Mental Health and Addictions Leadership Advisory Council highlighted the need for improved data collection and management across all mental health and addictions services. They point out that without a more complete, evidence-based understanding of services available across publically funded services and supports, we cannot definitively know the extent of service gaps or where improvement is needed. Likewise, the Auditor General's 2016 report identifies gaps in wait time data collection for publically funded supportive housing for mental health, resulting in challenges identifying, and consequently responding to, unmet need.

Quality, comprehensive and accessible data is necessary for identifying service inefficiencies, providing evidence of service gaps and promoting transparency and accountability across the mental health and addictions sector. At the same time community agencies may not have the resources to efficiently and effectively capture and manage data and may require support for implementing data collection and management tools and strategies.

As such SSO recommends that targeted funding include investment to improve the data management infrastructure for mental health and addictions in Ontario.

Conclusion

SSO commends the Ontario government for its considerable work to improve the health and quality of life of people experiencing mental illness and their families. We support the various strategies and initiatives underway to ensure that people have access to the treatments and supports they need to live healthy, fulfilling lives which in turn helps to create a healthy, resilient society.

We do urge the government to use Budget 2017 as an opportunity to make an investment to ensure that these critical plans can be realized.

In light of mental health being included within broader Canadian health funding discussions it is the opportune time for Ontario to lead by example and, regardless of the outcomes reached by Health Accord deliberations, to raise the amount of health and social spending respectively dedicated to mental health and addictions by two per cent.

We welcome any future opportunity to elaborate on our perspectives and recommendations. For questions, please contact Erin Boudreau, manager of policy and community engagement, at eboudreau@schizophrenia.on.ca or 1-800-449-6367 x 255.